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IN THE
Supreme Court of the United States
OCTOBER TERM, 1989

NANCY BETH CRUZAN, by her parents and co-guardians, LESTER L. and JOYCE CRUZAN,
Petitioners,
v.
DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH, and ADMINISTRATOR OF THE MISSOURI REHABILITATION CENTER AT MT. VERNON,
Respondents,
v.
THAD C. McCANSE, Guardian Ad Litem,
Respondent.

On Writ of Certiorari to the Supreme Court of the State of Missouri

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BRIEF OF SOCIETY OF CRITICAL CARE MEDICINE, PRESBYTERIAN-UNIVERSITY HOSPITAL, AND TRUSTEES OF THE UNIVERSITY OF PENNSYLVANIA AS *AMICI CURIAE* IN SUPPORT OF PETITIONERS

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QUESTION PRESENTED

Whether the decision of the Missouri Supreme Court denying petitioner the power, through her parents and co-guardians, to refuse continuation of life-sustaining medical treatment, is incompatible with the public policy of maintaining the ethical integrity of the medical profession, and violates petitioner's constitutional right of privacy?

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INTEREST OF *AMICI CURIAE*

Amici curiae are an organization of health care professionals, and two hospitals employing or affiliated with numerous health care professionals. Many of the members, or professional employees or affiliates, of each *amicus* are involved in the care and treatment of critically ill,

critically injured, or dying patients. All such health care professionals share in common and abiding dedication to promote the public welfare through the maintenance of the highest professional and ethical standards and the provision of quality health care.

Amicus Society of Critical Care Medicine ("Society") is a private, voluntary, non-profit, multi-disciplinary, multi-professional organization formed in 1970 by specialists from Anesthesiology, Internal Medicine, Pediatrics and Surgery. From 28 individuals the Society has grown in 19 years to over 3400 persons, including physicians, nurses, respiratory therapists, pharmacists, scientists, technologists, engineers, and persons working in health-related industries. Members of the Society blend the knowledge, skill and technology from the four medical specialities, nursing, and allied health professions into a coordinated effort to achieve an optimal outcome for critically ill or injured patients. The goals of the Society include improving humane care for patients with acute life-threatening illness and injuries, promoting and developing optimal facilities in which Critical Care Medicine may be practiced, and assuring high educational standards in Critical Care Medicine.

Amicus Presbyterian-University Hospital is a private non-profit hospital with 636 licensed beds, and is a major provider of adult acute health care including specialty services in neurology and neurosurgery, oncology, organ transplantation, emergency medicine and trauma, cardiology, orthopedics, nephrology, and pediatrics. Founded in 1893, the Hospital is a leading academic medical education and research center, employing approximately 600 full-time physicians and 1500 nursing staff, and providing facilities to more than 800 interns and residents. The hospital performs more organ transplants, and more types of transplants, than any other hospital in the world. The Hospital also serves as a teaching hospital for the University of Pittsburgh School of Medicine and the other schools of the health sciences.

Amicus Trustees of the University of Pennsylvania is a private, non-profit educational institution and the owner and operator of the Hospital of the University of Pennsylvania, in whose interests the Trustees have joined this brief. The Hospital opened in 1873 and, with the University School of Medicine, was the first teaching hospital in the country. It has 701 licensed beds, employs more than 600 active staff physicians and more than 1,000 nurses, and is a national leader in patient care, education, and research.

Amici's interest in this case stems from the desire of their members and professional employees and affiliates to provide medical care of the highest quality, their dedication to good medical practice and maintaining the ethical integrity of the medical profession, and their commitment to the dignity and autonomy of individual patients by preserving the freedom of patients to choose whether or not to receive medical treatment. To further these interests, health care professionals must be in a position to discharge their responsibilities to offer care and treatment according to the best clinical judgment consistent with professional and ethical standards. Similarly, patients and their families must be free to exercise the patient's right to informed consent or refusal to care and treatments offered, including life-sustaining treatments. *Amici's* interest is not in debating the philosophical, ethical, moral, or religious issues surrounding a patient's refusal of life-sustaining medical treatment. *Amici* do, however, share an interest in making certain that, when a patient does face the issue of whether to accept or decline life-sustaining treatment, state laws do not impermissibly interfere with the ability of treating health care professionals to carry out the patient's informed decision in a manner consistent with the best ethical and professional standards and the patient's particular health needs.

The decision of the Missouri Supreme Court in this case interferes with the patient's right to decline unwanted medical care and treatment, and prevents health care pro-

fessionals from providing medical care consistent with prevailing medical, ethical, and professional standards. The outcome of this case will directly affect the professional services *amici* or their members, or professional employees or affiliates will provide and the patients whom they serve. Accordingly, *amici* wish to present their views concerning the important issues raised in this case.[1]

ARGUMENT

In the decision below, the Missouri Supreme Court held that Nancy Cruzan's right of privacy under the United States Constitution, if it existed, was not absolute, but had to be balanced against the state's interests to the contrary. *Cruzan v. Harmon*, 760 S.W.2d 408, 419 (Mo. 1988). The court identified four such interests: preservation of life, prevention of homicide and suicide, protection of innocent third parties, and the maintenance of the ethical integrity of the medical profession. *Id.* Concluding that only the state's interest in the preservation of life was implicated by Nancy Cruzan's situation, the court held that this state interest outweighed Nancy's right of privacy, assuming that right was infringed upon. *Id.*

The Missouri Supreme Court's decision is flawed in two fundamental respects. First, as shown in Section I below, the court's "balancing" of interests is unsound due to its failure to consider the state's acknowledged public policy interest in maintaining the ethical integrity of the medical profession.[2] While not in itself a basis for reversing the decision of the Missouri Supreme Court, the well-established ethical tradition of respect for patient autonomy by medical professionals evidences a public policy weighing heavily against the "unqualified" interest in preservation of life pronounced by the court. *Id.* at 420. This public policy, deeply rooted in our Nation's history and tradition, is part of the foundation of the constitutional right of privacy described in Section II. This second section demonstrates that the Missouri Supreme Court's decision must be reversed because it violates Nancy Cruzan's right of privacy.

I. THE DECISION OF THE MISSOURI SUPREME COURT IS INCOMPATIBLE WITH THE PUBLIC POLICY OF MAINTAINING THE ETHICAL INTEGRITY OF THE MEDICAL PROFESSION.

Prevailing ethical standards among physicians[3] require that the decisions of a patient with decisionmaking ca-

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[1] Pursuant to Rule 36 of the Rules of this Court, the parties have consented to the filing of this brief. The parties' letters of consent have been filed with the Clerk of the Court.

[2] The Missouri Supreme Court was correct in concluding that the other state interests listed were not implicated by this case. It is a well-accepted medical and legal judgment that withholding or withdrawing life-sustaining medical treatment is not the equivalent of homicide (euthanasia) or assisting suicide. As stated in the report of a major institute for the study of medical ethical issues, "[m]edical tradition and customary practice . . . [do] not hold the health care professional morally responsible for the death of a patient when life-sustaining treatment is refused and the professional's purpose is not to cause death, but to honor the refusal." The Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying* 128-29 (1987) ("Hastings Center Report"). *Accord, The Appleton Consensus: Suggested International Guidelines for Decisions to Forgo Medical Treatment*, 151 Ugeskrift For Laeger (Journal of the Danish Medical Association) 700, 703 (1989) ("*Appleton Consensus*"); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-Sustaining Treatment* 38-39 (1983) ("President's Commission Report") (Commission has not found any instances in which civil or criminal liability imposed on health care professionals or others for acquiescing in patient's decision to forego life-sustaining treatment).

Likewise, where, as here, the patient's family and legal representatives all concur in the decision to withdraw treatment, there can be no harm to innocent third parties by honoring that decision.

[3] *Amici* have focused their attention in this brief on the ethical code of physicians for three reasons. First, it ordinarily will be the treating physician or physicians who are in a position to give

pacity [4] regarding the withholding or withdrawing of life-sustaining medical treatments, including artificially-supplied nutrition and hydration, be fully respected, whether or not the patient currently retains such capacity. Because it denies physicians the authority to respect such decisions, the Missouri Supreme Court's decision represents an unwarranted violation of the medical profession's ethical integrity.

A. A Physician Has An Ethical Obligation, Deriving From Respect For The Dignity And Autonomy Of The Patient, To Secure The Informed Consent Of The Patient Prior To Rendering Medical Treatment, And To Terminate Such Treatment Upon The Patient's Request.

The role of the physician in our soeiety follows a long and honorable history. Several fundamental ethical principles are clear. Physicians generally must strive both to preserve life and to relieve suffering. *See, e.g., Ruark,*

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the orders that will withhold or withdraw life-sustaining medical treatments or bear the continued care of a patient whose decision to withhold or withdraw medical treatment has not been honored. Second, as the acknowledged leaders of the health professions, physicians have generated a more clearly documented set of standards than other health care professionals. Finally, *amici* believe that the prevailing standards of ethical conduct applicable to physicians are consistent with those applicable to other health care professionals, and therefore represent the appropriate standards to be applied by other professionals.

[4] As used in this brief, the term "decisionmaking capacity" (or "capacity") has the meaning given it by the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions* (1982): "(1) possession of a set of values and goals; (2) the ability to communicate and to understand information; and (3) the ability to reason and to deliberate about one's choices." *Id.* at 56-57. The term is used in lieu of legal "competence," because *amici* do not wish to imply that a judicial determination of competence or incompetence is necessary to trigger the decisionmaking processes outlined in this brief.

et als., Initiating and Withdrawing Life Support: Principles and Practice in Adult Medicine, 318 N. Eng. J. Med. 25, 26 (1988) ("Ruark"). These two obligations are often described collectively as the principle of beneficence. *Appleton Consensus* at 701. Physicians also must be cautious to provide treatment in accordance with the principle of non-maleficence, expressed in the maxim, *primum non nocere*: "first do no harm." Ruark at 26; *Appleton Consensus* at 701. Medical commentators generally agree that together, these principles obligate the physician to provide treatment that will be more beneficial than burdensome to the patient. *E.g., Appleton Consensus* at 701; Lynn & Childress, *Must Patients Always Be Given Food and Water?*, The Hastings Center Report 17, 18 (October 1983) ("Lynn & Childress").

Finally, and most importantly for purposes of the case at bar, physicians are bound to honor the principle of patient autonomy, which finds its most common expression in the physician's obligation to obtain the "informed consent" of the patient prior to rendering any treatment. *E.g.*, American Medical Association, *Opinions of the Council on Ethical and Judicial Affairs of the American Medical Association*, 8.07 (1986) ("AMA Opinions"); Hastings Center Report at 19; United States Office of Technology Assessment, *Life-Sustaining Technologies For The Elderly* 23 (Box 1-A) (1987) ("OTA Report"); President's Commission Report at 43-44.

These principles of medical ethics may occasionally conflict, leading to an ethical dilemma. For example, the principle of autonomy may conflict with the principles of beneficence or non-maleficence if a patient desires a particular treatment that the treating physician believes will be of no benefit, or will be detrimental. In this instance, the obligation to provide treatment that is more beneficial than burdensome prevails: the care available from health care professionals "is generally limited to what is consistent with role-related professional standards

and conscientiously held personal beliefs. . . . No one . . . has an obligation to provide interventions that would, in his or her judgment, be countertherapeutic." President's Commission Report at 44; Brett & McCullough, *When Patients Request Specific Interventions*, 315 N. Eng. J. Med. 1347 (1986).

The outcome of the ethical dilemma is reversed, however, when the issue is whether or not to provide a particular treatment that the physician, or some one other than the patient, believes will be beneficial, and the patient refuses such treatment. In this instance, respect for the autonomy of the individual, as manifested in the principle of informed consent, demands that the patient's decision be respected and followed.

The resolution of this last ethical dilemma—the one presented by the case of Nancy Cruzan—is illustrated in the Opinions of the AMA Council on Ethical and Judicial Affairs ("AMA Council"). As noted above, the physician's social commitment includes the often-related obligations to strive to sustain life and to relieve suffering. *Id.*, 2.18. "Where the performance of one duty conflicts with the other, *the choice of the patient, or his family or legal representative if the patient is incompetent to act in his own behalf, should prevail.*" *Id.* (emphasis supplied). Thus, it is the physician's ethical obligation to honor the choice of the patient in determining whether a particular treatment is more burdensome than beneficial. In other words, where the issue is whether to accept or forego treatment, the controlling ethical obligation of the physician is to honor the patient's decision.

It is not surprising that the principle of patient autonomy, manifested in the requirement of obtaining informed consent to medical treatment, is the cornerstone of the treatment decisionmaking procss. The first of the Ethical Principles adopted by the AMA Council states that a physician shall be dedicated to providing competent medical service "with compassion and respect for

human dignity." AMA Opinions at ix. The fourth such Principle binds the physician to "respect the rights of patients." *Id.* There is broad agreement within the profession that proper respect for the dignity and rights of patients means first and foremost that the decision whether to accept or forego treatment is for the patient alone. As two medical-ethical commentators have put it, "any violation of strongly expressed patient wishes would constitute an affront to dignity." Thomasma and Pellegrino, *The Role of the Family and Physicians in Decisions for Incompetent Patients*, 8 Theoretical Medicine 283, 285 (1987) ("Thomasma & Pellegrino"). The physician's obligation to preserve patient dignity thus demands that the patient's decision to forego medical treatment be honored.

Medical commentators have found the root of the ethical principle of patient autonomy in treatment decisionmaking in the more general respect which the medical profession, and our society generally, hold for the autonomy of the individual to make the choices that will affect the course of his or her life. "A liberal society respects persons by permitting them to realize their ultimate ends whether others regard them as worthy or foolish. In medical care, this means patients must ultimately decide whether they want a particular medical intervention or not." Emmanuel, *A Review of the Medical and Legal Aspects of Terminating Medical Care*, 84 Am. J. Med. 291, 292 (1988). *See also* Mill, *On Liberty* 13 (Macmillan ed. 1985) (1859) ("the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others"). The physician's obligation to honor "the patient's right to self-decision," *id.*, thus has its roots deep in our Nation's history and tradition.

That the final decision whether to accept or forego treatment belongs to the patient is not to say that the physician has no role in the decisionmaking process.

"Informed consent" is a two-part process: the patient *consents* based on his or her subjective value system and the *information* provided by the physician. In the treatment of many conditions, the physician may not be in a position to recommend a single "best" course of treatment, but may present several options. The patient's choice may depend on his or her feelings about which side effects are more burdensome (*e.g.*, treatment of breast cancer by surgery or chemotherapy and radiation therapy), as much as on the chances of the treatment's success.

Thus, while agreeing that the final decision must be the patient's, several medical commentators have emphasized the importance of a dialogue between physician and patient to assist the patient in arriving at a decision as to a course of treatment. *See, e.g.*, Thomasma & Pellegrino at 285; President's Commission Report at 43-60. The American Medical Association has endorsed this position unequivocally:

> The patient should make his own determination on treatment. The physician's obligation is to present the medical facts accurately to the patient or to the individual responsible for his care and to make recommendations for management in accordance with good medical practice. . . . Social policy does not accept the paternalistic view that the physician may remain silent because divulgence might prompt the patient to forego needed therapy.

AMA Opinions, 8.07.

The physician's important role in the decisionmaking process points up another important aspect of the ethical duty to honor the patient's treatment decisions. As noted above, the physician has no duty to provide treatment which he or she believes to be inappropriate. *See supra* pp. 7-8. Thus, where the patient demands such treatment, the physician is ethically bound to refuse. A corollary to this rule must be that where the physician and patient *concur* that further treatment is not called for, an even

higher ethical imperative counsels against providing such treatment.[5]

In sum, firmly rooted in the respect of the medical profession for human dignity, the principle of patient autonomy is one of the fundaments of medical ethics. The state's public policy interest in maintaining the ethical integrity of the medical profession thus demands that this principle be honored.

B. The Ethical Obligation To Honor A Patient's Decision To Forego Medical Treatment Applies To Refusal Of Life-Sustaining Medical Treatment.

Nowhere is the principle of patient autonomy placed under greater strain than in the area of withholding or withdrawing life-sustaining medical treatments. Here, the physician's social commitment to sustain life may conflict with a patient's wish that his or her life not be sustained by artificial means under certain circumstances. So important is the principle of autonomy, however, that there is broad consensus that it applies even to the right to refuse life-sustaining medical treatments. *See, e.g.*, President's Commission Report at 43-44; Hastings Center Report at 7, 19; Presbyterian-University Hospital, Guidelines on Foregoing Life-Sustaining Treatment (May 1985) ("Presbyterian-University Hospital Guidelines"), *reprinted in* Meisel *et als., Hospital guidelines for deciding about life-sustaining treatment: Dealing with health "limbo"*, 14 Critical Care Medicine 239, 243 (1986); Providence Medical Center, Guidelines On Foregoing Life-Sustaining Treatment (June 28, 1985); *Appleton Consensus* at 702-03. Indeed, one recent study of the attitudes of clinicians found that the most important factor in their decision whether to begin artificial nutrition

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[5] This ethical imperative also has an important practical consequence. Where the patient (or the patient's surrogate) and physician concur in the desirability of withholding or withdrawing treatment, a rule of law *requiring* continuation of such treatment may find few willing followers in the medical profession.

(tube feeding) was the preference of the patient. Smith & Wigton, *Modeling Decisions to Use Tube Feeding in Seriously Ill Patients*, 147 Arch. Intern. Med. 1242 (1987).

The AMA Council also has specifically considered this issue. The Council analyzes the issue as presenting a conflict between two aspects of the physician's social commitment: the duty to sustain life, and the duty to relieve suffering. AMA Opinions, 2.18. In the Council's view, the duty to relieve suffering may encompass permitting a patient, exercising informed consent, to refuse life-sustaining medical treatment. "Where the performance of one duty [to sustain life] conflicts with the other [to relieve suffering], the choice of the patient, or his family or legal representative if the patient is incompetent to act in his own behalf, should prevail." *Id.*

C. The Ethical Obligation To Honor The Patient's Decision To Forego Life-Sustaining Medical Treatment Does Not Depend On The Presence Of A Terminal Illness.

The medical community is likewise in agreement that the patient's right to choose whether to accept life-sustaining treatment does not depend upon the patient being terminally ill. Although this is often the context in which such decisions arise, "a patient need not be terminally ill or imminently dying for these decisions to be ethically permissible." Hastings Center Report at 5. The President's Commission specifically rejected the presence of "terminal" illness as a decisionmaking factor. President's Commission Report at 24-26.

In accordance with the principle of patient autonomy, the Commission noted that the proximity of death may seem very different to different patients, and that predicting with any certainty the end of a person's life is a "notoriously uncertain" art. *Id.* The Commission concluded that "[i]t seems difficult to devise or justify policies that restrict people's discretion or to make appropriate decisions by allowing some choices only to "terminally ill" patients or by denying them other choices." *Id.* at 26. Accordingly, ethical medical practice requires that medical professionals respect a patient's treatment decision to refuse treatment whether or not the patient is "terminally ill."

D. The Ethical Obligation To Honor The Patient's Decision To Forego Life-Sustaining Medical Treatment Applies Equally To Decisions To Withhold Treatment Initially, And To Withdraw Treatment Already Begun.

Nor is the principle of patient autonomy diminished when the issue is whether to withdraw treatment already begun, rather than whether to withhold or begin treatment in the first place. Some health care professionals traditionally considered it more acceptable not to begin treatment than to withdraw treatment once begun. *See, e.g.*, President's Commission Report at 73-74. The Commission properly attributes this attitude to the related notion that to bring about death by *action* is more morally heinous than to do so by *omission*. *Id.* Stopping treatment already under way seems more akin to the former, and thus could be seen as more immoral.

As the Commission points out, however, considerations of morality actually cut the other way. Most significantly, an ethical or legal rule that makes withholding treatment more acceptable than withdrawing treatment could deter the commencement of treatment that might prove beneficial. In many instances, experience with a treatment is necessary to establish whether it will be beneficial, either alone or in conjunction with other potential treatments. Physicians must remain free to offer and withdraw multiple treatments based on their effectiveness and the views of the patient. For this reason, the Commission concludes that the same considerations of patient autonomy and informed consent should guide decisions to withhold or to withdraw treatment. This

view now is widely shared in the medical profession. *See* AMA Opinions, 2.18; Hastings Center Report at 130-31; American Academy of Neurology ("AAN"), Position of the American Academy of Neurology on Certain Aspects of the Care and Management of the Persistent Vegetative State, IV (1989) ("AAN Statement") (reproduced in Appendix to Brief of *Amicus Curiae* American Academy of Neurology in Support of Petition for a Writ of Certiorari); *Appleton Consensus* at 702-03; *Presbyterian-University Hospital Guidelines, reprinted in* Meisel *et als.* at 243.

E. The Ethical Obligation To Honor The Patient's Decision To Forego Life-Sustaining Medical Treatment Applies To Artificial Nutrition And Hydration.

What constitute "medical treatments" for purposes of applying the patient's right to forego them? There is broad agreement that artificial nutrition and hydration are medical treatments for this purpose. President's Commission Report at 90; AMA Opinions, 2.18; Hastings Center Report at 59-60; Steinbrook & Lo, *Artificial Feeding—Solid Ground, Not a Slippery Slope*, 318 N. Eng. J. Med. 286, 288 (1988); Ruark at 30; Presbyterian-University Hospital Guidelines, I, *reprinted in* Meisel *et als.* at 243.[6]

[6] The Missouri Supreme Court stated that "[t]here is *substantial* disagreement on this point among *physicians* and ethicists." 760 S.W.2d at 423 (emphasis supplied). In support of this statement, the court cited the trial testimony of one physician. *Id.* The court also attempted to illustrate its point by citing statements of other *amici* organizations, to the effect that nutrition and hydration ought not be treated as medical treatments for this purpose. *Id.* at n.19. However, none of the organizations whose briefs were cited for this proposition purport to represent the views of *physicians*. *Amici* respectfully submit that the Missouri Supreme Court's own authorities amply support the contrary proposition: that there is no substantial disagreement among physicians as to the status of artificial nutrition and hydration as medical treatments.

Several commentators have pointed out that there is an important psychological value, to a patient's family or treatment team, to providing food and water to the sick. *See, e.g.*, Lynn & Childress at 17. But treatment of the patient should be undertaken for the purpose of promoting the patient's interests, not simply to ameliorate the feelings of others. Further, nutrition and hydration provided through nasogastric, gastrostomy, or intravenous tubing are not eating and drinking. They are technological processes, accomplished by surgical procedures, that provide fluid and nutritional material when the ordinary human processes of swallowing, ingestion, or digestion have failed. As such, they cannot meaningfully be distinguished from other technological processes that replace failed body organs or systems. As with these other technological advances, the decision whether to forego them must be based on whether the benefits of treatment outweigh its burdens in the view of the patient. *Id.* at 18.

F. The Ethical Obligation To Honor The Patient's Decision To Forego Life-Sustaining Medical Treatment Applies To Patients Who Once Had, But No Longer Possess, Decisionmaking Capacity.

As explained above, the patient's right to choose whether or not to forego medical treatment derives from the respect of the medical profession, and of our society generally, for the dignity and autonomy of the individual. It is a fundamental component of that respect that a patient retains his or her individual dignity and autonomy even after neurological damage or degeneration destroys the patient's decisionmaking capacity.[7] *See, e.g.*, Presbyterian-University Hospital Guidelines, IV, *re-*

[7] *Amici* recognize that somewhat different considerations might operate for a patient who has never had decisionmaking capacity. Without taking a position on this issue, *amici* note simply that their remarks are addressed only to the issue facing the Court: that of an individual who once had, but no longer possesses, decisionmaking capacity.

printed in Meisel *et als.* 241, 245. Accordingly, due respect for the patient's autonomy demands that the patient's decision to forego life-sustaining medical treatment be respected even after the patient no longer has the capacity to state or reiterate that decision.

The ethical consensus in the medical profession adopts this view. The AMA Council's Opinions provide that "[a] competent, adult patient may, in advance, formulate and provide a valid consent to the withholding or withdrawal of life-support systems in the event that injury or illness renders that individual incompetent to make such a decision." AMA Opinions, 2.19. *Accord*, Hastings Center Report at 26-29, 78-84; Presbyterian-University Hospital Guidelines, V, *reprinted in* Meisel *et als.*, 245-46; Providence Medical Center, Guidelines On Foregoing Life-Sustaining Treatment (1985).

A more complex problem is presented when the patient has failed to leave explicit instructions while in possession of decisionmaking capacity. There is consensus within the medical community for how such a patient's wishes should be honored.

The Hastings Center Report suggests a structure for such decisionmaking which is in accordance with the AMA Council's position, with the President's Commission Report, with the *Appleton Consensus*, and with good, ethical medical practice. In general terms, the methodology recommended would permit a surrogate decisionmaker to determine whether the burdens of life-sustaining medical treatment would be viewed *by the patient* to outweigh its benefits.

In consultation with other members of the treatment team, the physician with primary responsibility for the patient's care, in accordance with policies adopted by the institution housing the patient, must identify a surrogate decisionmaker. Hastings Center Report at 24-25; President's Commission Report at 126-32. *Cf. Appleton Consensus* (treating physician to act as surrogate).

Where the patient has not previously identified a surrogate, and there is no court-appointed surrogate with the requisite authority,[8] the physician should turn to a member of the patient's family, or close friend. Hastings Center Report at 24-25; President's Commission Report at 126-27. The object, as explained in the *Appleton Consensus*, is to choose from among those persons "who are available and competent, have been involved with and concerned about the patient, are knowledgeable about the patient's preferences and values, and are willing to apply the patient's values to making the decision." *Appleton Consensus* at 702.

The surrogate's first duty is to apply the patient's preferences and values, based on what is known, attempting to choose as the patient would have wanted. President's Commission Report at 132-34, 136; Hastings Center Report at 28; *Appleton Consensus* at 702. This standard for decision is often called a "substituted judgment" standard. President's Commission Report at 132; *Appleton Consensus* at 702. The basis for a substituted judgment decision should be any reliable evidence that the surrogate has about the patient's specific views, or, when these are not known, on the patient's general values, goals, and desires. President's Commission Report at 133-34.

If not enough is known to permit a responsible substituted judgment decision, the surrogate should choose to promote the patient's interests as they would probably be conceived by a reasonable person in the patient's circumstances. President's Commission Report at 134-36;

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[8] *Amici* do not contend that court appointment is required or even desirable. Rather, *amici* merely take the position that if legal processes have been invoked, the resulting appointments must be honored. *Amici* believe the recommendations of the President's Commission are in accord with medical ethics and the best medical practice, that "the cumbersomeness and costs of legal guardianship strongly militate against its use. . . ." President's Commission Report at 131.

Hastings Center Report at 28; *Appleton Consensus* at 702. This corresponds to the AMA Council's "best interests" standard. AMA Opinions, 2.18. Guideposts for making this decision might include, for example, the belief that ordinarily, "persons would want to preserve identity, be able to maintain independence and control, be able to interact with others, have pleasurable experiences, avoid pain and suffering, and avoid being a severe burden upon others." *Appleton Consensus* at 702; *see also* President's Commission Report at 182-83.

A surrogate decisionmaker is not, of course, a perfect substitute for the patient. In addition to the difficulty of accurately exercising a patient's substituted judgment, or even of determining what a reasonable person in the patient's situation would choose, there is the possibility that the surrogate might have a conflict of interest with the interests of the patient. *See*, Areen, *The Legal Status of Consent Obtained from Families of Adult Patients to Withhold or Withdraw Treatment*, 258 JAMA 229, 232-33 (1987). Because of the possibility of conflict of interest, good medical practice requires that the decision of a surrogate to withhold or withdraw life-sustaining medical treatment be subject to challenge in circumstances where it appears that the surrogate's decision has been reached in ignorance or in bad faith. *See id.* at 234. As Professor Areen suggests, there would be a presumption in favor of the surrogate's decision, but one that could be challenged for good reason. *Id.* Ideally, consensus should be reached among the surrogate, the patient's family, and the treatment team. A variety of administrative mechanisms for resolving challenges, including consultation with religious advisors or a hospital ethics committee, would comport with good medical practice. *See* Hastings Center Report at 32; *Appleton Consensus* at 702.

G. The Ethical Obligation To Honor The Patient's Decision To Forego Life-Sustaining Medical Treatment Applies To A Patient In A Persistent Vegetative State.

Finally, there is broad agreement that when a patient is irreversibly unconscious, the prior expressed preference of that patient, who then had decisionmaking capacity, to forego life-sustaining treatment should be honored. As the AMA Council has put it:

> Even if death is not imminent but a patient's coma is beyond doubt irreversible and there are adequate safeguards to confirm the accuracy of the diagnosis and with the concurrence of those who have responsibility for the care of the patient, it is not unethical to discontinue all means of life-prolonging medical treatment.

AMA Opinions, 2.18. A commentator employed by the AMA elsewhere has explained that persons in a persistent vegetative state ("PVS") are in an irreversible coma within the meaning of this opinion. Rymer, *Courts Differ on Disposition of Patient's Right to Die Cases*, 58 The Citation 92 (1989). Relying on the President's Commission Report, the AMA commentator notes that PVS patients lack any awareness of their environment, "[p]ersonality, memory, purposive action, social interaction, sentience, thought, and even emotional states . . . pain and suffering . . . joy, satisfaction, and pleasure." *Id.* (quoting President's Commission Report at 174-75, 180-81).

The view that life-sustaining treatment must ethically be withdrawn or withheld, in accordance with the prior expressed wishes of the PVS patient, is shared by the AAN. As explained in the AAN's official position statement, PVS is "a form of eyes-open permanent unconsciousness in which the patient has periods of wakefulness and physiologic sleep/wake cycles, but at no time is the patient aware of himself or his environment." AAN Statement, I. The statement explains that primitive re-

flexes, such as breathing, are present because the patient's brain stem remains functional. However, all voluntary functions and more complex reflexes are absent, due to the total loss of cerebral cortical functioning. The AAN states that the diagnosis of PVS can usually be made with a high degree of medical certainty in cases of hypoxischemic encephalopathy [9] after a period of one to three months. The AAN has also concluded that patients in PVS do not experience pain or suffering, which are attributes of consciousness requiring cerebral cortical functioning.

Accordingly, in the view of the AMA and the American Academy of Neurology, the PVS patient is in a state in which a medical professional may, indeed must, ethically honor the stated preference of a patient with capacity to forego life-sustaining medical treatment. AMA Opinions, 2.18; AAN Statement, III.[10]

H. Summary.

Prevailing medical ethical standards require that physicians honor the decisions of patients concerning whether

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[9] A degenerative condition of the brain brought on by oxygen deprivation.

[10] Many medical professionals would go further. In 1988, Lawrence University sponsored a program entitled "Proceedings of Guidelines for Non-Treatment Decisions: An International Working Conference." Thirty-three delegates (twenty-five physicians representing eleven different medical specializations, seven bioethecists and one medical economist) from ten different countries participated in drafting *The Appleton Consenus: Suggested International Guidelines for Decisions to Forgo Medical Treatment*, 151 Ugeskrift For Laeger (Journal of the Danish Medical Association) 700 (1989). The delegates agreed that the patient who has been reliably diagnosed as PVS "has no self-regarding interests. Unless the patient in the past has requested or the family or caregivers now can justify continuing life-sustaining treatments, there is no reason to use those treatments." *Id.* at 703. Five delegates dissented from this language, stating that they were "unable to accept a categorical statement which rules out life-sustaining treatments." *Id.* at 705.

to accept or forego medical treatment, including life-sustaining artificial nutrition and hydration. The foundation of these standards—the respect of the medical profession for the dignity and autonomy of each patient—demands that they apply just as forcefully to patients who once had, but no longer possess, decisionmaking capacity. The ethical integrity of the medical profession thus depends on maintaining the freedom to participate with patients and their families (and the surrogates of patients without decisionmaking capacity) in decisions concerning the foregoing of life-sustaining medical treatment, and to honor those decisions once made by or on behalf of a patient.

II. THE DECISION OF THE MISSOURI SUPREME COURT VIOLATES NANCY CRUZAN'S CONSTITUTIONAL RIGHT OF PRIVACY.

This Court's cases recognize that the federal Constitution contains a right of privacy that prohibits the state from interfering with an individual's exercise of certain basic freedoms which are deeply rooted in this Nation's history and tradition. Cases from other courts have held that the patient's interest in retaining the decisional autonomy to forego life-sustaining treatment is such a freedom.[11] Because it unduly burdens Nancy Cruzan's

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[11] The principles of medical ethics described above—that respect for the dignity and autonomy of an individual require a physician to obtain the informed consent of the patient or the patient's surrogate prior to rendering medical treatment, and to honor the decision of the patient or surrogate regarding the withdrawal of such treatment—have found expression in the common law of the states. As the Missouri Supreme Court recognized, it has long been well-established that a battery occurs when a physician performs a medical procedure without valid consent. *Cruzan*, 760 S.W.2d at 417. This principle applies as well to the continuation of a procedure once the patient has withdrawn consent. However, the Missouri court concluded that under the common law of that State, this right could not be exercised under "hypothetical circumstances." *Id.* Thus, the court apparently held that in Missouri, the common law right to informed consent to medical treatment does not permit an individual with decisionmaking capacity to leave

exercise of this right, the decision of the Missouri Supreme Court must be reversed.

A. The Cases Of This Court Recognize A Right Of Privacy Which Protects, Among Other Things, The Bodily Integrity Of The Individual Where Protection Of Such Integrity Is Deeply Rooted In This Nation's History And Tradition.

In a line of cases beginning with *Griswold v. Connecticut*, 381 U.S. 479 (1965), this Court has recognized that an unenumerated right of privacy deriving from various provisions of the federal Constitution prohibits the state from interfering in an individual's free choice of whether and how to engage in certain intimate activities. Under *Griswold*, the decision protected is whether a married couple will make use of contraceptives; under *Roe v. Wade*, 410 U.S. 113 (1973), and its progeny, the decision protected is whether a pregnant woman will carry a fetus to term, or submit to an abortion; under an earlier case, *Skinner v. Oklahoma*, 316 U.S. 535 (1942) (later recognized in *Griswold*, 381 U.S. at 485, to deal as well with the right of privacy), the decision protected is whether to procreate.

A common thread connecting all of these cases is that the Constitution protects individuals from many state-ordered invasions of or control over their persons. While the Court has declined to go so far as to find "an unlimited right to do with one's body as one pleases," *Roe*, 410 U.S. at 154, or to extend the right of privacy to *all* decisions implicating bodily integrity, *Bowers v. Hardwick*, 478 U.S. 186 (1986) (right to privacy does not encompass right to engage in homosexual sodomy), the Court has consistently recognized that the interests qualifying for protection under the right of privacy include "those fundamental liberties that are 'implicit in the concept of ordered liberty,' such that 'neither liberty nor justice would exist if [they] were sacrificed.'" *Bowers*, 478 U.S. at 191-92 (quoting *Palko v. Connecticut*, 302 U.S. 319, 325-26 (1937)). Fundamental liberties that are "deeply rooted in this Nation's history and tradition" are protected by the right of privacy. *Bowers*, 478 U.S. at 192 (quoting *Moore v. City of East Cleveland*, 431 U.S. 494, 503 (1977) (Opinion of Powell, J.)).

Both of these formulations of the interests protected by the right of privacy are descriptive of the interest of a patient in deciding for himself or herself whether to submit to or forego medical treatment. It is difficult to imagine that liberty or justice could exist in a society that so ignored the dignity and autonomy of an individual that the law permitted (or, as here, required) medical practitioners to perform unwanted medical treatments on his or her person. Moreover, as the above discussion of the ethical obligations of the medical profession amply demonstrates, the rights of patient autonomy and informed consent, broadly embraced by the medical profession, are "deeply rooted in this Nation's history and tradition." *Bowers*, 478 U.S. at 192.

B. Cases From Other Courts Have Concluded With Near Unanimity That The Right Of Privacy Necessarily Includes The Right To Forego Unwanted But Life-Sustaining Medical Treatments.

Only one federal court so far has considered the question of whether the constitutional right of privacy encompasses the decision whether to forego unwanted but life-

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instructions concerning the sorts of medical treatments—life-sustaining or not—to which that individual refuses consent. The court also held that the Missouri constitution confers no "unfettered" right of privacy such as would permit the withdrawal of Nancy Cruzan's nutrition and hydration, *id.* at 417, and that the right conferred under the State's living will statute does not extend to refusal of nutrition or hydration. *Id.* at 419-20. Because Missouri law is so restrictive, the only protection available to a Missouri resident who wishes to refuse in advance to be kept alive by artificial nutrition or hydration should he or she enter a state of irreversible unconsciousness must be found in the federal Constitution.

sustaining medical treatment. In *Gray v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988), the federal district court considered the case of Marcia Gray, a 49 year-old woman in a persistent vegetative state due to a cerebral hemorrhage. Her husband and legal guardian sought a declaratory judgment authorizing him to direct the hospital housing his wife to remove the gastrostomy tube that provided her with artificial nutrition and hydration.

In a thoughtful opinion, the trial court concluded that Marcia Gray's right of privacy included the right to refuse life-sustaining medical treatment. *Id.* at 586. The court also concluded that nutrition and hydration supplied through a gastrostomy tube were a form of medical treatment that could properly be refused. *Id.* Finally, recognizing that the "value of human dignity" extends to both competent and incompetent patients, the court concluded that Marcia Gray's right to forego life-sustaining nutrition and hydration could be exercised by a court-appointed Guardian *Ad Litem*. *Id.* As explained above, each one of these decisions by the court permitted the exercise of Marcia Gray's right of privacy in a manner wholly consonant with the ethical standards of the medical profession. *See supra* pp. 6-21.

Numerous decisions from the courts of other states have reached the identical conclusions regarding the scope of the right of privacy, and the manner of its exercise on behalf of a person who has lost decisionmaking capacity. *See, e.g., In re Drabick*, 200 Cal.App.3d 104, 245 Cal. Rptr. 840 (Cal. App. 6 Dist.) (upholding right of family member as surrogate to order withdrawal of artificial nutrition and hydration from PVS patient), *cert. denied*, 109 S.Ct. 399 (1988); *Brophy v. New England Sinai Hospital, Inc.*, 398 Mass. 417, 497 N.E.2d 626 (Mass. 1986) (same); *In re Colyer*, 99 Wash.2d 114, 660 P.2d 738 (Wash. 1983) (upholding right of family member as surrogate to order withdrawal of respirator from PVS patient); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647

(N.J.) (same), *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976).[12] Accordingly, as even the Missouri Supreme Court acknowledged, the great weight of judicial authority is to the effect that the constitutional right of privacy encompasses the right of a person who has lost decisionmaking capacity, through a surrogate, to forego life-sustaining medical treatment, including artificial nutrition and hydration. *See Cruzan*, 760 S.W.2d at 412 n.4 and accompanying text (citing cases).

C. While Reasonable Regulation In Areas Protected By The Right Of Privacy Is Permitted In Support Of Other Important State Interests, Such Regulation May Not "Unduly Burden" Exercise Of The Right.

The decisions of this Court also recognize that the right of privacy is not absolute. The Court stated in *Roe* that "some state regulation in areas protected by that right is appropriate." 410 U.S. at 154. As the Court

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[12] The Missouri Supreme Court makes much of the assertion that the right recognized in *Quinlan*, the leading case in this area, was limited "to circumstances in which the patient is terminally ill." *Cruzan*, 760 S.W.2d at 415, 421. The court seemed critical of the "everbroadening" application of the right in subsequent cases to persons who were not terminally ill. *Id.* at 421. While not specifically approving the decision in *Quinlan* itself, the court's characterization of that case as demonstrating "restraint" suggests that it is the application of the right to patients not terminally ill after *Quinlan* that is truly problematic. *Id.* at 415.

Amici note that the Missouri Supreme Court's premise is flawed. In only one of the three cases cited by the court was the patient terminally ill. *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (Mass. 1977) (death predicted to occur in a matter of weeks or months without treatment). Karen Quinlan was a PVS patient, of whom the court found that "exactly how long she would live without [her respirator] is unknown." *Quinlan*, 355 A.2d at 655. Similarly, in *In re Storar/In re Eichner*, 52 N.Y.2d 363, 438 N.Y.S.2d 266, 420 N.E.2d 64 (N.Y.), *cert. denied sub nom. Storar v. Storar*, 454 U.S. 858 (1981), the patient for whom the court upheld the decision to withdraw life support was a PVS patient. The New York Court of Appeals made no finding that he was terminally ill.

made clear only last term in the context of the right to choose an abortion, state regulation in support of "'important and legitimate' interests" is permissible, even in an area protected by the right of privacy, as long as such regulation "does not impose an undue burden on a woman's abortion decision." *Webster v. Reproductive Health Services*, 57 U.S.L.W. 5023, 5030 (Opinion of Rehnquist, J., three justices concurring), 5031 (Opinion of O'Connor, J.) (July 3, 1989).

In *Webster*, a majority of five justices agreed that Missouri's law requiring a woman seeking an abortion after the twentieth week to submit to certain tests to determine if the fetus is viable did not unduly burden the woman's liberty to exercise her right. In the context of the instant case, therefore, Missouri may constitutionally regulate the exercise of the right to forego life-sustaining medical treatment in support of other state interests, so long as its regulations do not "unduly burden" the exercise of the right. Examination of the Missouri Supreme Court's decision conclusively demonstrates that Missouri law, as pronounced by that court, is unduly burdensome to the exercise of the patient's right to forego life-sustaining medical treatment.

D. The Missouri Supreme Court's Decision Unduly Burdens Exercise Of The Right Of Privacy By Denying Any Right To Withdraw Life-Sustaining Nutrition And Hydration.

The constitutional right to refuse further life-sustaining medical treatment, by withdrawing nutrition and hydration supplied through a gastrostomy tube, cannot be exercised in the State of Missouri. This is so because the Missouri Supreme Court has found that the State's "unqualified" interest in life, *Cruzan*, 760 S.W.2d at 420, is so powerful that it will virtually always overcome the patient's right to refuse treatment. According to the Missouri Supreme Court, the issue is not whether artificial nutrition and hydration are medical treatments which can properly be refused. The issue rather "is whether feeding and providing liquid to Nancy is a burden *to her*." *Id.* at 423 (emphasis in original). Although the court's standard is an appropriate one, its application of that standard to Nancy's situation creates a rule of law that violates the ethical integrity of the medical profession and the right of privacy.

The Missouri Court based its decision on two grounds. First, the court found that the evidence of Nancy's preferences was "woefully inadequate" to permit a court to approve a substituted judgment decision. *Id.* at 424. Second, the court found that, even assuming sufficient evidence were available, the State's "unqualified" interest in life would overcome the expressed preference of an individual to forego life-sustaining treatment unless it could be shown that such treatment was more "burdensome" than beneficial to the individual. *Id.* The court later equates "burden" with pain to the individual. *Id.*

On the question of evidence, the trial court found that about a year prior to the accident which caused her condition, Nancy had expressed to her housemate the feeling "that she would not wish to continue living if she couldn't be at least halfway normal." *Id.* at 433 (judgment of trial court quoted in dissenting opinion of Higgins, J.). Her family and friends described Nancy as a "vivacious, active, outgoing, independent person who preferred to do for herself." *Id.* Based upon Nancy's own expression, upon this description of her life style, and upon "other statements to family and friends," the court found by clear and convincing evidence that Nancy "would not wish to continue her present existence without hope as it is." *Id.*

In holding that, as a matter of law, evidence such as this is insufficient to permit the exercise of substituted judgment by a surrogate decisionmaker, the Missouri court rejects the accumulated ethical wisdom of the medical profession. As described above, medical professionals would honor the decision of a surrogate to withdraw life-

sustaining medical treatment on the basis of reliable evidence of the patient's specific views, and when these are not known, of the patient's general values, goals, and desires. *See supra* p. 17. Nancy's statements to her housemate—an individual with no incentive to dissemble —certainly constitute "reliable evidence" of Nancy's specific views under any normaitve understanding of the term. The court's other findings—of Nancy's vivacious, active, outgoing and independent nature—likewise constitute "reliable evidence" that her general values, goals, and desires would be incompatible with a vegetative existence, and further support her housemate's description of her views.

Moreover, the Missouri Supreme Court's decision would never permit a "best interests" judgment to be made by a surrogate. The court's decision thus condemns the PVS patient who, like most, has not executed some formal expression of his or her preferences, to a long vegetative existence, regardless of the affront to dignity which that person would feel at being artificially maintained in such a state.

More important, even if the court were prepared to accept *some* evidence of the patient's preferences as sufficient to permit the exercise of substituted judgment, the court's opinion would permit the withdrawal of artificial nutrition and hydration only if it could be shown that continued treatment was "burdensome", i.e., painful, to the patient. As the AAN Statement demonstrates, PVS patients are insensible to pain; consequently, the court's standard could *never* be met by a PVS patient. Such an absolute prohibition of a particular course of conduct within an area protected by the right of privacy is the clearest case imaginable of a regulation which is "unduly burdensome" to the exercise of that right, in violation of the principle set forth in *Webster*.[13]

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[13] It is clear that Missouri's living will statute cannot be employed to make a formal expression of a contrary preference. That statute specifically exempts artificial nutrition and hydration from the list of treatment processes that a person may direct to be withheld or withdrawn. *See Cruzan*, 760 S.W.2d at 419-20. While the constitutionality of that statute need not be at issue if the right of privacy permits alternative means for a person to direct that such treatments be withheld or withdrawn, the statute would be unconstitutional if it were the exclusive means for directing the withholding or withdrawing of treatment in that State. *See supra* note 11.

The Missouri Supreme Court's error is its arbitrarily narrow definition of what sorts of medical treatment an individual might regard as "burdensome." Nancy Cruzan's family and Guardian *Ad Litem* have concluded that Nancy would believe the burdens *to Nancy* of a persistent vegetative existence—without feeling, emotion, thought, pleasure, or hope of recovery, and sustained by artificial nutrition and hydration—outweigh any benefits of continued treatment. Nancy's body also is burdened by the presence of the artificial feeding tube, and might be subjected to future invasive procedures if infection ensues. The tube's access site might break down, requiring additional surgery. While she would not feel the physical pain associated with these events, they would be debilitating to her overall physical condition, degrading even further the state to which the Missouri Supreme Court has condemned her. Under these circumstances, it is highly reasonable for Nancy's family and co-guardians to have concluded that *Nancy* would find the burdens of artificial nutrition and hydration to outweigh its benefits, and choose to have these treatments discontinued.

While decrying the right of any person to assume another's "right of privacy choices" in the absence of "clear and convincing, inherently reliable evidence," *Cruzan*, 760 S.W.2d at 425, the court's decision does precisely that. By its decision that the only potential burden that could justify the surrogate exercise of Nancy's right to forego life-sustaining medical treatment would be physical pain to Nancy, the court simply assumes the role

of surrogate decisionmaker itself, and performs its own exercise of substituted judgment on Nancy's behalf.

The Missouri Supreme Court has no better knowledge as to what would be Nancy Cruzan's preferences in this matter than her family, friends, and Guardian *Ad Litem*. Moreover, by rejecting the collective judgment of those individuals, arrived at in consultation with the medical professionals involved in Nancy's case, the court has created a rule of law fundamentally at odds with the ethical obligations of the medical profession. Amici respectfully submit that the rule of law created by the Missouri Supreme Court is at odds with the public policy of maintaining the ethical integrity of the medical profession, and with the constitutional right of privacy.

CONCLUSION

For the foregoing reasons the decision of the Missouri Supreme Court should be reversed.

Respectfully submitted,

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